Book, Video, and Film Reviews

Bowling, Ann. *Research Methods in Health: Investigating Health and Health Services*. Buckingham, England: Open University Press (Distributed by Taylor & Francis, Inc., 47 Runway Rd., Suite G, Levittown, PA 19057-4700; 1-800/821-8312), 1997, 447 pages, $31.95 softcover.

Reviewed by Jae Kennedy, Ph.D., Assistant Professor, Department of Community Health, University of Illinois at Urbana-Champaign.

I have been looking for a new book for my graduate research methods course in the Department of Community Health at the University of Illinois and, therefore, was excited to be killing two birds with one stone by doing this review. I tried to look through the eyes of my students (mostly bright young people without a lot of research background) when reading this book. To cut to the chase, I concluded that I liked it more than most of them would and doubt that I will use it next spring. I am pleased to have a copy, however, and would recommend it to other researchers and academics.

The content is generally thorough, well written, and well grounded in theory. The book has 17 chapters, broken into five major sections: 1) "Investigating Health Services and Health" (which covers basic concepts in medical sociology, epidemiology, and health economics); 2) "The Philosophy, Theory, and Practice of Research" (a general introduction to the premises and mechanics of scientific research); 3) "Sampling and Research Methods" (a fairly detailed analysis of sampling and measurement issues); 4) "Tools of Quantitative Research" (a very extensive and useful discussion of issues involved in development, administration, and interpretation of health surveys); and 5) "Qualitative and Combined Research Methods" (an overview of observational studies, focus groups, and case studies).

The author is from the University of London and most of the health services examples are drawn from the National Health Service, a system that differs dramatically from the American "system(s)." Though one could hardly describe health care in the U.K. as apolitical, the degree of intellectual and political turmoil is muted in comparison to ours. This may account for the relatively even scientific tone of the text which could be helpful for instructors trying to disentangle the science of research from the politics of health care. However, some content gaps would probably need to be filled to provide a thorough research introduction for American graduate students.

Though there is a brief discussion of human subjects review, ethical issues in research are not discussed in sufficient detail. As is evident from the section descriptions above, the text focuses on survey research techniques. This is understandable, given the author's highly regarded work in health measurement (she has written an excellent book on quality of life instruments), but it limits the utility of the text for some types of aspiring researchers. Overall, however, this is a thoughtful, thorough, and praiseworthy effort.

I do not want to end on a sour note, but I must mention that the tops of some pages had not been completely cut in my review copy of *Research Methods in Health*. I had to use a ruler as a bookmark, and constantly whack it through the rough perforations at the top of the pages, often tearing them. If I had paid $31.95 for this paperback, I would have been furious and probably would have returned it. Let us hope that this was an isolated problem, but caveat emptor. Nonetheless, I am glad I persevered and my tattered copy will remain on an accessible shelf where I expect to refer to it regularly.

Clare, Eli. *Exile and Pride: Disability, Queerness, and Liberation.* Cambridge, MA: South End Press (7 Brookline St., #1, Cambridge, MA 02139-4146; 617/547-4002), 1999, 158 pages, $40.00 hardcover, $14.00 softcover.

Reviewed by Kate Kaul, Social and Political Thought Programme, York University.

The title of *Exile and Pride* suggests an attempt at the intersection of disability and

queerness, but, in Eli Clare's exploration of territory, class, community, language, activism, and identity (to name just a few terms that did not fit into the title) things get much more complicated than that. This is a politically demanding and often poetic book; its uneasy position recalls the author's characterization of herself as "mixed-class" - not quite middle-class, not quite poor - and this is only one of the identity categories that Clare describes as inadequate to experience. Clare's writing is most impressive in the descriptions of her relationship to the land on which she grew up.

Readers of DSQ may be more familiar with some of the disability issues that Clare addresses than with her keenly critical environmental politics, although her reading of disability, as an experience and a history, is never extricable from a mesh of political concerns. In the chapter "Freaks and Queers," Clare's discussion of naming leads her through disability definitions and etymology to a tracing of the unsettling effect of the word "freak" and its history, as well as to a reading of "freak" against "queer," which includes a careful distinction between two responses to histories of oppression and resistance: pride and bearing witness.

Clare's most consistent achievement in this somewhat uneven text is the way she avoids generalization in her questions about disability, queerness, and liberation, grounding these larger categories in the particularity of her personal experience. This is a rare and valuable attempt to inquire into what Clare calls "the connective tissue that brings queer, class, and exile together" (p. 44), even if there are moments when this book seems to be trying to bring too many things together. The reader is asked to follow Clare from the disability rights movement, child sexual abuse, and queer and transgender identities, to the politics of class, race, and community, to critiques of urban activism, capitalism, and imperialism. But, of course, things really are this complicated: "...everything piling finally into a single human body" (p. 123).

Clare's text demonstrates both the fragility and the strange persistence of identity, following a dramatically individual, particular self through a difficult and rich history.

Clark, David, and Seymour, Jane. *Reflections on Palliative Care.* Buckingham, England: Open University Press (Distributed by Taylor & Francis, Inc., 47 Runway Rd., Suite G, Levittown, PA 19057-4700; 1-800/821-8312), 1999, 223 pages, $28.95 softcover.

Reviewed by Debra Sheets, Andrus Gerontology Center, University of Southern California, Los Angeles, CA.

This book is one in a series that is bringing attention to the developing field of palliative care - other books in the series focus on spiritual issues, research, bereavement, and quality of life issues affecting death and dying. Clearly, how we think about death, dying, and bereavement has been profoundly affected by the aging of populations in modern societies. The authors note that modern death is generally associated with old age, is invisible or absent from personal experience, and is typically managed by medical experts.

The book is divided into four sections. Part I identifies key themes that affect our sociological understanding of death and dying. As a starting point for the rest of the book, these three chapters provide an insightful and fascinating exploration of the process of dying by examining aging, informal care, bereavement, and end of life issues. Part II provides a detailed overview of the historical development of the philosophy and practice of palliative care. The chapters in this section discuss the hospice movement, establish a definition for palliative care, and consider the meaning of the "good death." This section also addresses the debate on whether the hospice and palliative care movement has fallen victim to "routinization" and "medicalization" as it has become institutionalized and more bureaucratic. The issues and their complex interrelationships are addressed clearly and thoroughly.

In Part III the focus shifts to policy issues that are having an impact on palliative care and the settings in which it is provided. These chapters show how the modern hospice relates to the National Health Service in the United Kingdom. It examines delivery of pallia-

tive care services in homes, hospices, and institutional homes, and the evidence for its effectiveness in meeting the needs of individuals. In the final part of the book, the authors consider the future for palliative care and argue for a broadening of the vision, expansion of the agenda, and efforts to promote the principles and practices to other societies and cultures.

This book is a valuable contribution and should be essential reading for anyone interested in death and dying issues. The authors bring sociological, historical, and policy perspectives to palliative care, while writing in a clear and accessible style. The main limitation of the book is that the policy chapters primarily reflect policy issues in the United Kingdom, which are of limited use in the United States.

Davis, Lennard, J., ed. *Shall I Say a Kiss? The Courtship Letters of a Deaf Couple, 1936-1938*. Washington, DC: Gallaudet University Press, 1999, 191 pages, $ 29.95 hardcover.

Reviewed by Alexa Schriempf, University of Oregon.

Shall I Say a Kiss? is a collection of the courtship letters of the parents of Lennard Davis, found after his father's death, with an introduction and an afterword by Davis. What is most remarkable about this collection is the absence of Deaf and deaf issues (that is, the cultural world as well as the biological condition). One should definitely read the introduction again after the letters as a number of crucial, but easily overlooked elements of the letters are brought to light. Without Davis' analysis, it would have been difficult for someone brought up in today's society to understand the significance of the historical, social, and identity issues presented in these letters. Both Morris Davis and Eva Weintrobe were British, working-class, Jewish, deaf individuals; neither one saw any aspect of their identities as deserving more attention in particular in contradistinction to today's prevailing fascination with multiple identities.

Unfortunately, all but a few of Morris' letters are lost. We are left with Eva's side the courtship, which, as Davis notes, reveals a side of his mother he never knew existed. In the course of her letters, we see Eva's life unfold as she deals with multiple issues: Morris' pursuit of her hand in marriage from overseas in America, her family's initial reluctance about her marriage, the U.S. Immigration barrier against Jewish and disabled individuals, communication between the deaf and hearing worlds, and, somewhat humorously, a brief affair with the wealthy "Leeds boy" that threatened the courtship.

It takes a sharp and attentive eye to catch the subtlety of Eva's tone as it changes from formal letters to coquettish endings such as "Shall I say a kiss?" But it takes an even sharper eye to envision the world behind these letters - one in which U.S. Immigration has just passed restrictions on who can enter the U.S. (Morris gained entry before this), the economy is in a depression, and World War II looms on the surface.

The apparent lack of interest in the public world outside of the deaf community is not in the least due to ignorance or isolation. Rather, as Davis suggests, the letters are "a story... that takes place almost entirely within an identity community" (p. 174). The community is the Deaf community and these letters hold the story of that world. "The absence of these [public] events in the letters only shows even more how the Deaf world, particularly during the prewar period was one defined not by electronic communication but the immediate environment" (p. 175). These letters, then, serve as a unique, first-hand account of the particular Deaf-world in 1930s Liverpool. The correspondence, combined with Davis' excellent introduction and closing, provides us with a Deaf-enriched account of life during pre-World War II Europe that has otherwise gone unnoticed in history.

Einhorn, Lois J. *Helen Keller, Public Speaker: Sightless but Seen, Deaf but Heard.* Westport, CT: Greenwood Press, 1998, 182 pages, $55.00 hardcover.

Reviewed by Lois Bragg, Gallaudet University, Washington, DC.

Helen Keller was the Chris Reeve of her day, and the Jerry Lewis as well, an enormously popular entertainer whose public "speaking" tours supported her and her entourage

of handlers and hangers-on while raking in the cash to support workfare programs for the hearing and seeing, that is to say, the organizations by, of, and for people who make careers off the deaf, disabled, and poor. That the performance staged at each stop in these tours bore greater resemblance to the typical freakshow of the period than a public lecture should escape no one in Disability Studies. The damage that these tours did to the struggles of disabled people for respect, autonomy, and civil rights was incalculably enormous.

Einhorn's short anthology of selected speeches of Keller's, thus, promises fascinating reading and a valuable opportunity to assess Keller's deleterious effect on public opinion. As a Deaf scholar myself, I focus here on Keller's remarks about the Deaf community. Because Keller declined all overtures from the NAD (National Association of the Deaf) and knew no sign language, she had no authority to speak for Deaf people, and there is, therefore, delicious irony, as well as deep sadness, in her addresses to (hearing) oralists, particularly in that her own articulation made her almost wholly incomprehensible to anyone but her handlers. For example, in 1896, when she herself was a student at Radcliffe with a full-time personal interpreter, she addressed a convention of oralist teachers held at the Pennsylvania School for the Deaf (during the summer holidays when all the Deaf pupils would be safely off campus) on the topic of "The Value of Speech for the Deaf," concluding with the claim that "we shall speak, yes, and sing, too, as God intended we should speak and sing" (p. 81). If God himself endorsed oralism, then, naturally, one ought not to listen to the protests of actual Deaf people, who, according to Keller in a 1914 performance, "do not realize the wretchedness of their condition [and] are incapable of desiring improvement. God help them!" (p. 94).

Unfortunately, Einhorn proves to be unequal to the task of even placing Keller's politics and rhetoric in context, let alone providing any analysis. She actually omits noting the audience for any speech, providing only the date and a sketchy locale, and she appears to be wholly unacquainted with any views published by other deaf and disabled people that would illuminate for her how far out of touch Keller was. Her 13 page bibliography includes not one single article from the Deaf presses. Even more troubling than such editorial lapses is Einhorn's denigration of Deaf people and our language, as when she writes, for example, of the six-year-old Keller, "Like an animal, [she] used crude signs to convey basic desires" (p. 11). That academic discourse positing such bigoted and ignorant notions of a Deaf child's home signs should be published in 1998 is appalling.

It is very interesting to note that Einhorn has omitted any sample of Keller's public addresses in support of eugenics, an able-ist pseudo-science of Keller's day bent on eliminating people like Keller herself. Keller's fervid endorsement of eugenics and its hateful propositions appears in Einhorn's discussion only in passing, and under the euphemism "birth control" (p. 23)! This is dishonest. Clearly, Keller's politics and rhetoric and the enormous damage she did to the dignity and civil rights of disabled people demand the attention of scholars in Deaf and Disability Studies, who, unlike Einhorn, should have the knowledge and the courage to address this dark figure of our history and put an end to the cult she apparently still commands.

Fetterman, David M. *Ethnography: Step by Step* (Second Edition). Thousand Oaks, CA: Sage Publications, 1998, 175 pages, $42.00 hardcover, $18.95 softcover.

Reviewed by Diane Weiner, Professional Research Anthropologist, UCLA American Indian Studies Center.

Last month I began anthropological fieldwork on breast cancer detection and treatment strategies in a new region among members of an American Indian ethnic group divided amongst several reservations and linked, in part, through a health consortium. I have been doing ethnographic research with a variety of Native communities since 1981 when I was a senior in college. In 1996 I commenced a series of exploratory studies on American Indian

cancer beliefs and behaviors that formed the basis for several health interventions.

So, with a mixture of skepticism, based on my years of experience, and gratitude, founded on the realization that every anthropological project is a unique journey of learning, I read *Ethnography: Step by Step*. This text is a helpful overview of anthropological methods for newcomers to the field and for those who wish to re-assess their current modes of research.

Fetterman incorporates his decades of research, teaching, and evaluation experiences to create a brief methods text. Separated into seven sections, the book provides 1) an introduction to ethnography and fieldwork, 2) basic concepts about ethnography and anthropology, 3) data collection methods, 4) research equipment, 5) data analysis, 6) the art of ethnographic writing, and 7) ethical concerns. A reference section that includes seminal studies of the field as well as lesser-known works is also included. In each part the author comments on particular techniques or ideas. In the chapter on data collection, there are overviews on fieldwork, sampling, entry into a community, participant observation, interviewing styles, psychological tests, photography, written information, body language, and folk tales. These topics are enlivened by examples based on Fetterman's prior work and by the value and possible pitfalls of these strategies.

Fetterman has conducted research in Israel and in urban schools throughout the United States. The examples he offers are generally based on people who live on kibbutzim and on urban school children and not on disabled people per se; however, the knowledge and tools Fetterman describes may be applied to investigations of most any topic with members of many communities. For example, a description of participant observation techniques Fetterman used on a kibbutz and in Jerusalem could easily be attempted in a project with individuals in rural Maine who have multiple sclerosis, with the aging residents of a New York building, or with other individuals.

This book will surely aid students and other scholars being introduced to fieldwork. Nevertheless, it should be accompanied by additional texts that intensely explore each topic reviewed by Fetterman. For more advanced students of ethnography, the sections on technology and ethics will prove worthwhile. The author's excitement prompted me to create new interview questions and reconsider data analysis methods. Indeed, I may switch software this month!

Ethnography: Step by Step will be kept accessible so that my students and I may refer to it.

Handler, Lowell. *Twitch and Shout: A Touretter's Tale*. New York, NY: Plume (Penguin Putnam Inc.), 1999, 212 pages, $12.95 softcover.

Reviewed by Johnson Cheu, Department of English, The Ohio State University, Columbus, OH.

Handler provides readers with a method for reading his memoir. He writes in the introduction, "The incidents in *Twitch and Shout* may not follow a strict chronology. Instead, some events of my life are highlighted or spotlight [sic] through the prism of Tourette. Consider this memoir a series of frozen photographic frames, given as much movement and depth with words as I have been able to summon" (p. xxvi). Handler, a professional photographer with Tourette (with some LD and ADHD thrown in), makes much of his relative inability with language compared to more imagistic ways of making meaning.

Indeed, much of this book reads journalistically without many extended scenes. For instance, his brief marriage is highlighted in a couple vignettes, but its subsequent dissolution is largely summed up in his wife's one sentence: "I cannot do this anymore" (p. 168). And, besides Handler's comments, "My whole life was collapsing. . . . Susanna and I were resigned to the idea of divorce" (p. 168), there is little emotion to draw the reader in. Perhaps this is a result of Tourette, an impairment manifesting for Handler in jerks, fits, short phrases,

and twitches; it is natural that his memoir would be rather disjointed. If one can buy this idea and read *Twitch and Shout* the way Handler asks readers to do, this book will be a much easier sell.

Handler has led quite an interesting life and much is touched on here from his childhood, his struggles for independence, his life as a professional photographer, his meeting of and relationship with Oliver Sacks, to his involvement in the documentary "Twitch and Shout." Besides being a memoir about Tourette (a rarity), he explains much about the disability without didacticism. For those who want to "look in" on a "Touretter," or who want a non-medical take on Tourette, or who are curious about the ubiquitous Dr. Sacks, this would be a good place to start. Still, the memoir does its most intriguing work when Handler attempts to explore his life and emotions. In a therapy session with his family dealing with his brother's cancer, the episode continues for several pages, allowing us glimpses of everyone in that room. It ends with a tearful admission of guilt on Handler's part. He writes, "Evan, it should have been me, I'm the defective one" (p. 86). He continues, "For a lifetime, I was the son with something 'wrong,' to whom all attention was drawn. Now I felt healthy because Evan was deathly ill, but maybe jealous because everything revolved around him. The situation of being in a weakened, disadvantaged position in a family can also be one of great power. The sick person has the potential to rule and also be a tyrant" (p. 86). Though *Twitch and Shout* has much in its favor, much of the time, I was left wanting more insights like this one.

Hood, Suzanne, Mayall, Berry, and Oliver, Sandy, eds. *Critical Issues in Social Research: Power and Prejudice*. Buckingham, England: Open University Press (Distributed by Taylor & Francis, Inc., 47 Runway Rd., Suite G, Levittown, PA 19057-4700; 1-800/821-8312), 1999, 187 pages, $26.95 softcover.

Reviewed by Ravi Malhotra, M.A., LL.B., Ottawa, Canada.

Occasionally one comes across a book that is insightful, articulate, intelligently written, and yet deeply frustrating for Disability Studies scholars and activists. An anthology of papers by scholars based, currently or in the past, at the University of London Institute of Education's Social Science Research Unit, this collection is precisely such a work. It consists of papers on a wide range of topics that, collectively, seek to interrogate and problematize social science research methods, primarily in the British context. Chapters straddle a wide variety of topics including children in the West and in developing countries, Black people's health, elderly people, people with learning disabilities (the British term for intellectual disability), gay men and HIV prevention, feminist history, and many others.

This is a worthy project, and, to a large degree, the authors consistently make challenging contributions that will be helpful to those seeking to swim steadily against the current of establishment epistemological frameworks. The authors are clearly knowledgeable in their various fields of research, and the reader can expect, despite the volume's brevity, to see intelligent use of and citation to scholars ranging from Hume to Giddens and from Rowbotham to Kuhn. The obfuscations of postmodernity are thankfully avoided while the crisp analysis still sheds light on important social problems in a critical and contextualized manner. While some books on this topic may be shrill in their ideological pontification, but far more shallow in the practical insights they offer, the various authors surprisingly manage to provide specific insights and case studies in their areas of expertise. Hence, we can read Helen Penn's fascinating, if esoteric, account of childhood services in Mongolia, including a tantalizing, yet all too brief, reference to children with disabilities. Chris Bonell's account of research on gay men in Britain and HIV prevention astutely refuses to counterpose a supposedly progressive qualitative approach with "reactionary" and qualitative research methods and argues that one can have progressive, well-informed research studies that are quantitative. In Christopher Goodey's chapter on learning disabilities we see a surprisingly philo-

sophical analysis of children with intellectual disabilities including cogent critiques of an all-knowing medical model that undervalues the lives of those with disabilities. Hence, Goodey passionately recounts how parents of one boy with Down syndrome sought to ensure that unsympathetic doctors who saw him as less than human did not withhold medical care when he caught common childhood illnesses.

Nevertheless, this book, unfortunately, is marred by its apparent lack of familiarity with the Disability Studies canon. Absent is Oliver or Morris or Barnes, let alone the American Disability Studies literature. If this book were simply an analysis that failed to include disability issues at all, that would be one thing. The book, in fact, almost entirely ignores those with physical disabilities. However, more disturbingly, this book, explicitly and implicitly, addresses some disability issues in at least a few chapters from a critical standpoint without demonstrating any awareness of Disability Studies or the disability rights movement. Hence, Sandy Oliver cites the merits of research instigated by lay people by providing, inter alia, the example of a study by Britain's Royal National Institute for the Blind (RNIB) on parents' experiences of the help and support they received when learning that their child was visually impaired. Yet, there is no mention that parental experiences might be at all problematic given the fact that most parents of disabled children do not have a disability themselves.

As the mandate of the book on social research methods from a critical perspective, this melding of the standpoint of nondisabled parents and their children with disabilities is rather surprising. It occurs again and again in the book when, in fact, the interests of children with disabilities and their nondisabled parents may conflict. Even Goodey's otherwise brilliant chapter, which cites work by the grassroots disability organization, People First, does not make this distinction clear. In other cases, such as Priscilla Alderson's chapter on children labelled as having emotional and behaviour disturbance, the entire analysis would have been enriched by a methodology that was cognizant of the Disability Studies literature and its very real analytical accomplishments.

Critical Issues in Social Research is definitely worth reading as a critique of third-rate positivist research and it contains a laudatory commitment to oppressed groups. Its analysis from a feminist, anti-racist, and gay positive perspective merits consideration and discussion, especially by those actively involved in designing social science research projects. This text would make a fine addition to the curriculum of many graduate seminars. Nevertheless, the lack of a coherent and overt acknowledgement of Disability Studies and the social-political model of disability is glaring and unfortunate. Disability Studies scholars, sadly, will have to wait for a new text on social research methods to address these vital issues.

Hunter, Marlene E. *Making Peace with Chronic Pain: A Whole-Life Strategy*. New York, NY: Brunner/Mazel Publishers (Distributed by Taylor & Francis, 47 Runway Rd., Suite G, Levittown, PA 19057-4700; 1-800/821-8312), 1996, 190 pages, $18.95 softcover.

Reviewed by Tanis Doe, Ph.D., Pearson College, Victoria, BC, Canada.

One of the reasons the social model of disability is hard to embrace is the phenomenon of pain. One of the difficulties around the construct of Disability Culture is the experience of organic discomfort. Some people have a hard time incorporating a very true experience of hurt with a celebration of identity or the social construction of disablement. I am proudly part of a Deaf and disability culture, but I am also one of many people with disabilities who feels pain and seeks treatment for it. This book being reviewed, *Making Peace with Chronic Pain*, is in some ways a guide to self-treatment, but, more importantly, could be a significant contribution to understanding pain through a social model lens.

The author, Marlene Hunter, is a medical doctor and therapist who has treated many people with acute and chronic pain and she purposely chooses the word "sufferer" to

describe people in pain. She explains very clearly that there are at least two components to pain: the physiological and the suffering. The physiological relates to the stimulus that sends information through neuropathways to respond or to warn the brain. This is, in fact, the protective or useful reaction to intrusion, inflammation, or damage. The alarm tells the person that there is a problem and that she or he must attend to this problem. The suffering component relates directly to how much the pain (the message of pain) intrudes on one's life. Using a metaphor of "dance," which is expanded on throughout the book, the author sets the stage of pain. Of particular note here is that the author directs our attention not exclusively to the individual experiencing pain (the sufferer), but to all those involved in "directing or choreographing" the pain. The family, the doctor, the pharmacist, the employer, the children, the insurance adjuster, and the social worker are all part of the experience of dealing with the physiological and suffering aspects of pain. The reaction of the public to the individual who is in pain has a direct impact on how difficult it is to live with or manage the pain. This is, to me, a great application of the social model of disability (impairment?).

One of the definite advantages of acute pain is how time-limited it is. Another is that, usually, it can be dealt with pharmaceutically. Local and even general anesthetics, narcotics, and analgesics are often successful in treating severe, but acute, pain. These same approaches are often ineffective or unrecommended for long-term chronic pain. Hypnosis, relaxation, mechanical strategies, and cognitive/coping skills are discussed as positive options for people dealing with ongoing, unrelenting, intrusive pain. The author recommends these as ways to address the "suffering" as well as the physiological components when medical strategies fail. One of the keys to successful management of pain, explained in the text, is that pain itself is a "dissociative" experience. "Just ask people who have been ill for an extended period of time and they will tell you that it is as if the illness has taken over their minds and bodies. There seems to be a separation - some part of themselves is linked to the illness or pain and the other parts are not" (p. 5). The intrusion of pain into people's lives has a great deal to do with the "taking over."

People's social roles - worker, mother, lover, brother, athlete - are either taken away or significantly altered when someone is medicated so heavily for pain that they sleep all day. Chronic pain is sometimes, but not always, connected to movement or exertion, which makes returning to activities, exercising, or even daily life excruciating. Or, when pain causes a lack of sleep, anxiety, and ongoing fatigue, the person simply cannot function as he or she wants to, is expected to, and previously could. It is this part of the book's discussion of pain that succeeds in addressing the difficulty of the social model. The book never suggests that pain is pretended, imagined, or caused by the sufferer, but it does directly address the relationship between society, family, stress, personality, and the experience of pain. The physiological pain is seen by the author (and experienced by the sufferer) as existing within a social context. A major portion of the consequences of pain is constructed by medical and social policy - how much medication is allowed, how much time off is allowed, what is a reasonable recovery period, who is helping at home, financial compensation, diagnostic codes, and insurance schedules. Family and friends are also directly related and the author addresses what is called "secondary gain" in a constructive way.

For a great many people with disabilities, it is insulting to suggest that we are somehow benefiting from being in pain. The very nature of pain itself is uncomfortable and those of us who have had to approach a doctor for the umpteenth time with a pain complaint know how reluctant we are to admit we are "still" not feeling better. Yet, the fact is that the experience of pain does, in some cases, provide a much-needed distraction within families, workplaces, or social settings. Whatever underlying problems existed apart from the injury, illness, or disability related to the pain may be bypassed or, at least, postponed while the family members or workers address the immediate pain management issue. Because of this distraction effect, families tend to pull together, workers sympathize, and support systems

come into action where, previously, there may have been difficulties. This secondary gain weans itself over time, as acute or persistent pain becomes chronic. People's patience wears thin and the original problems resurface, perhaps with added resentment, when the pain overstays its welcome. People are "supposed" to get well. Disability, like chronic pain, does not go away, but must be lived with/experienced as part of life.

The text is easy to read and useful for people experiencing pain, their family and friends, and professionals treating pain. A chapter annotating journal articles and books is found at the end of the book along with a subject index.

Jenkinson, Crispin, ed. *Assessment and Evaluation of Health and Medical Care: A Methods Text.* Buckingham, England: Open University Press (Distributed by Taylor & Francis, Inc., 47 Runway Rd., Suite G, Levittown, PA 19057-4700; 1-800/821-8312), 1997, 197 pages, $29.95 softcover.

Reviewed by Raymond E. Glazier, Ph.D., Manager, Abt Associates Center for the Advancement of Rehabilitation and Disability Services, Cambridge, MA.

This book is, in essence, a collection of nine papers on different quantitative and qualitative evaluation techniques often applied in the analysis of health care issues ("Randomized Controlled Trials," "Case Control and Cohort Studies," "Social Surveys," "Qualitative Research Methods," and "Systematic Reviews and Meta-analysis") and categories of health care considerations ("Patient Assessed Outcomes: Measuring Health Status and Quality of Life," "The Assessment of Patient Satisfaction," "Economic Evaluation of Health Care," and "Evaluating Screening Programmes: Theory and Practice"). An introductory chapter focuses on a synopsis of each paper without managing to unify into a single text the works of thirteen authors drawn mainly from Oxford University.

The editor does point out in his introductory chapter that the randomized controlled trial remains the dominant method, harkening back, in a way, to the 18th Century clinical trial of six alternative treatments for scurvy tested by Lind on 12 British seamen, a trial that created their nickname "limies." The randomized control trials chapter by Shepperd, Doll, and Jenkinson is commendable in including discussions of withholding promising treatment from control subjects and other ethical issues concerning random assignment and the Hippocratic oath's admonition, "First, do no harm."

The distance between health services research design, addressed in this book, and disability research concerns of DSQ readers is, in most ways, minuscule except for the medical lingo most of us find abhorrent.

This small compendium of techniques provides a good introduction to the options for evaluation research design. However, the researcher will want to delve deeper into data analysis methods for the research design selected. The proper treatment of qualitative research methods would seem to require a separate volume; the single paragraph on focus groups (p. 111), for example, is not very enlightening. This is an excellent primer on the topic that demonstrates fairly comprehensively the wealth of options available. It would make a useful basic text in research methods courses.

Lesser, Rika. *All We Need of Hell: Poems.* Denton, TX: University of North Texas Press, 1995, 87 pages, $15.95 hardcover, $12.95 softcover.

Reviewed by Johnson Cheu, Department of English, The Ohio State University, Columbus, OH.

I will admit it, I have a bias. I am leery of any collection that provides a glossary. On the one hand, you want your work understood, particularly in this multicultural age, by as many readers as possible, hence the need for translation. On the other is the issue of realism. There was a similar argument about the TV show ER when it first aired: explain the medical language and procedures rolling off George Clooney's tongue for the audience or do not,

keeping to the "realism" of the show, and trust the audience. We know the road they chose, to great ratings success.

Reading Lesser's work, this same argument kept encroaching. Journeying through her depressive states and suicide attempts, knowing the medical terms, in a sense, did help. But I kept feeling that there might be better ways to convey her feelings than the confessional narrative structure imbued with medical jargon she often employs here.

Lesser is a noted writer, the author of a couple of volumes of poems, a few volumes of translations, and some "retellings for children" children's books. This book is no less ambitious in its scope. Not since, perhaps, Anne Sexton's inaugural collection, *To Bedlam and Part Way Back* (Cambridge, MA: Riverside Press, 1960), has mental illness been so thoroughly documented. There are, in fact, many nods to Sexton here: both collections include epistolary poems to their doctors. Sexton, though, did it better with lines like, "I tapped my own head;/it was glass, an inverted bowl/I will hold my awkward bowl,/with all its cracked stars shining/like a complicated lie" (*To Bedlam and Part Way Back*, p. 51). Lesser runs a bit more prosy, for example, in "A Valediction: Forbidding Moving": "If we were friends, I could/easily carry on; I'm an old hand/at managing distances. . . . You were more/than a friend or parent, asking nothing/for yourself. Nothing but this:/that I graciously let you go" (p. 33).

Lesser is at her emotional best here when she ponders her life where the medication, necessitating that glossary, serves as backdrop, not central metaphor. In "For Elisabeth," a moving contemplation of her relationship with her goddaughter, she achieves some of her best work. She begins, "What do I mean to tell you, you at six,/child not mine, the one child I will have?" (p. 74), continuing, "Happy child, how old will/you grow before you read this book? I grew/up with my nose in books, my mother's illness/before my shielded but seeing eyes, the weight of it pressing the life out of/my life, which, as someday you'll learn I/have tried to take" (p. 74). She imagines the grown-up Elisabeth's question to her upon reading this book: "What made you think I was so happy?" Lesser responds, "You did. Your joy was/contagious. It was your gift to me" (p. 75). If one can wade through the long narratives and medical jargon, Lesser's emotions and metaphors sprinkled throughout may prove, indeed, to be gifts for some.

McCubbin, Hamilton I., Thompson, Elizabeth A., Thompson, Anne I., and Futrell, Jo A., eds. *The Dynamics of Resilient Families*. Thousand Oaks, CA: Sage Publications, 1999, 293 pages, $49.00 hardcover, $24.95 softcover.

Reviewed by Rosalyn Benjamin Darling, Department of Sociology, Indiana University of Pennsylvania.

The Dynamics of Resilient Families is the fourth volume in the "Resiliency in Families" series, which, according to the series editor, "places the creation, integration, application, and dissemination of knowledge about the power of families of all forms, structures, ethnic groups, and cultures to recover from adversity as the highest priority on our agenda" (p. ii).

The volume consists of eight chapters on forms of "adversity" as diverse as infertility, having a family member with AIDS, and losing one's livelihood. Of these chapters, four relate directly to disability or chronic illness, including the ones on AIDS and infertility, one on diabetes, and one on "childhood chronic conditions." All of the chapters are based on qualitative research and, in keeping with the series theme, focus on positive consequences of adversity rather than on family dysfunction. The chapter authors come from a variety of academic backgrounds and most use an interdisciplinary perspective in developing their theoretical frameworks and research methods, although all are well grounded in the social science literature.

The idea of focusing on positive outcomes is not new. Back in 1983 I contributed a

chapter to an edited volume entitled *Life-Span Developmental Psychology: Nonnormative Life Events* (Edward J. Callahan and K.A. McCluskey, eds., New York, NY: Academic Press) which included chapters on rape, adolescent pregnancy, divorce, and childhood disability, among other unanticipated events. The theme of that volume was that events that present themselves as problems commonly become redefined as opportunities for growth. As I read *The Dynamics of Resilient Families*, I was constantly reminded of the earlier book and was happy to see its conclusions being supported by research conducted 16 years later.

Although only four chapters relate directly to disability, the processes described in the other chapters parallel the experience of adaptation to disability in many ways. For example, the redefinitional strategies used by families of unemployed fishermen are similar to those used by families of children with disabilities. Perhaps the major weakness of the book is the absence of a concluding chapter to pull together these common themes. Without any synthesis of the material in the various chapters, the reader is left to wonder about the possibility of a generic theory of family resiliency. Certainly, the material in the book would be valuable for psychologists, sociologists, and others interested in developing such a theory. For those simply interested in understanding the experience of disability in the family, the book provides some interesting, if not novel, insights.

Moore, Michele, Beazley, Sarah, and Maelzer, June. *Researching Disability Issues*. Buckingham, England: Open University Press (Distributed by Taylor & Francis, Inc., 47 Runway Rd., Suite G, Levittown, PA 19057-4700; 1-800/821-8312), 1998, 106 pages, $26.95 softcover.

Reviewed by Corinne Kirchner, American Foundation for the Blind.

I would classify this book as a methodological treatise, but that could be misleading if it makes potential readers expect a dry account of how to formulate hypotheses or design samples and so on. Instead, the authors try to "meet a need among researchers, including students, for rigorous reflection on inquiries concerning disabled people's lives" (p. 11). To these sensitive analysts, "rigorous" means a highly personalized account in which they do not spare their own research from criticism. They recount the painful learning experiences of situations in which their participation in conventional academic research "norms" and power relations functioned so as "to reproduce disadvantage, inequality and disablement" (p. 12).

But, while personal feelings enrich the telling, the book is not just an extended mea culpa. The document is clearly structured around its theme, summarized as "commitment" - a complex idea, the core of which, as used here, refers to the accountability of researchers while conducting specific studies. The authors open with a crystal clear values statement that calls for commitment to "maximiz[ing] the relevance of research for equality, inclusion and self-determination of disabled people" (p. 17).

Three subsequent chapters use actual research experiences to illustrate a progression from worse to better research models. While the authors demonstrate how traditional patterns of accountability by disability researchers lead to negative outcomes from the perspective of persons with disabilities, they suggest that realistic situations in which research auspices and designs move toward putting disabled people at the center of the power relations may still be problematic. Not surprisingly, one thread of discussion concerns the role of nondisabled researchers (two of the three authors self-identify as nondisabled), a sensitive issue that, here, is handled in an appropriately textured way. One comes away recognizing that many variables can override disability status in terms of influencing researchers' commitments, but that, ideally, committed persons with disabilities head up, or at least are central to, the research team.

Specifically, Chapter 2 describes "Conventional Commitment: Traditional Research and the Creation of Disablement"; Chapter 3 addresses "Divided Commitment: Researching with Service Users and Providers"; Chapter 4 highlights a more positive example, "Making

Commitment: Siding with Disabled People." Easy solutions are not implied, as Chapter 5 emphasizes in "Uncertain Commitment: The Interests of Children." The book ends on what might be considered an obligatory positive note (Chapter 6, "Developing New Pathways for Disability Researchers"), but, even here, the reader is forewarned that those pathways may be rocky. For example, we are alerted that, if we as researchers follow the authors' advice to be explicit about our values in support of the interests of people with disabilities, the results can be "harrowing if such declaration alienates the researchers from certain potential and powerful participants" (p. 93). Put more bluntly, you could lose your funding if you side too openly with the interests of the disabled participants.

Clearly, this is a thought-provoking book. Because of its self-revelatory nature and the candor about unresolved difficulties in meeting the ideal type of research commitments, reading it often seems like being in intense conversation with the authors. But, as noted above, the book has a didactic mission. It keeps coming back onto that less intimate track by means of a simple editorial device: periodically, there are boxed-off sections that spell out "Thinking Points." The device proved helpful to this experienced researcher and it also suggests that the book could be useful for students in the classroom context.

That the central theme is hardly original must be acknowledged. I went to my bookshelf to check a classic text: *Qualitative Analysis for Social Scientists* by Anselm Strauss (Cambridge, England: Cambridge University Press, 1987). There, back in 1987, Strauss stated, "In short, the researcher, if more than merely competent, will be 'in the work' - emotionally as well as intellectually - and often will be profoundly affected by experiences engendered by the research process itself" (p. 10). Nevertheless, this perspective merits re-stating in each research arena, and there is no doubt that it has been lacking in most academic and applied disability research until recently. The usual problem remains, that those researchers for whom these considerations might be most revolutionary and significant are those who probably will be the hardest to reach.

Pardeck, John T. *Social Work After the Americans with Disabilities Act: New Challenges and Opportunities for Social Service Professionals*. Westport, CT: Auburn House, 1998, 149 pages, $49.95 hardcover, $17.95 softcover.

Reviewed by Nancy R. Mudrick, Syracuse University.

Social workers and their agencies need to be familiar with the rights ensured by the ADA so that they can be better advocates with and for the people they are aiding - and so they can make sure that the programs in which they work are accessible to clients and employees with disabilities. This slim volume aims to inform social workers of the provisions, requirements, and implications of the ADA for social work. While I applaud its aims, the book is flawed in several areas.

The first half of the book describes the provisions of the ADA. Although the examples are specific to social work, the descriptive content repeats information available in the many free publications, brochures, web pages, and presentations about the ADA. In fact, some of the text in Pardeck's book is taken nearly verbatim from the question and answer material distributed by the Department of Justice.

In several places the author strongly states that disability under the ADA is determined without regard to the impact of mitigating measures (pp. 25, 31). In 1999 the Supreme Court came to the opposite conclusion (Sutton v. United Air Lines, 119 S. Ct. 2139). In fairness to the author, this book preceded the Supreme Court decision by a year. However, the strong statements suggest that the author was ignorant of the developing challenge to the interpretation of mitigating measures. At another point, Pardeck suggests that the reason a large proportion of EEOC complaints are from persons with invisible disabilities (e.g., bad backs and psychiatric disorders) is that employers are more fearful of discriminating against people with visible disabilities (p. 43). Pardeck seems unaware of the distribution of disabili-

ties in the population overall, a distribution quite similar to the distribution of disabilities among ADA Title I complainants.

The book also offers as a model an incorrect example of an ADA-compliant job description: must "possess manual dexterity necessary to operate a keyboard" and "communicate effectively verbally and in writing" (pp. 42-43). These phrases suggest the author misunderstands a fundamental aspect of the ADA and the disability rights movement. Job ads must focus on the function or task that needs to be performed, not on how it is performed (manually or orally).

There is some repetition of content across the chapters. This may also contribute to the sense of discontinuity. The generous use of lists is helpful at some points and too much at others. I would have liked to have seen a book with less description of the law and with more analysis of how it affects social workers and social work agencies. One gets a taste of the potential with the vignettes involving employees with disabilities in social work agencies. A more analytic treatment of the ways in which social work practice meets the ADA would be helpful.

Rogers, Cheryl, and Dolva, Gun. *Karina Has Down Syndrome: One Family's Account of the Early Years with a Child Who Has Special Needs.* London, England: Jessica Kingsley Publishers (Distributed by Taylor & Francis, Inc., 47 Runway Rd., Suite G, Levittown, PA 19057-4700; 1-800/821-8312), 1998, 112 pages, $17.95 softcover.

Reviewed by Peggy Quinn, School of Social Work, University of Texas at Arlington, and Karen Daly, Assistant City Manager, Longview, Texas (respectively, the grandmother and mother of Emma, who is 7 years old and has Down syndrome).

This small book is identified as a description of one family's experience with a child who has Down syndrome. It is written as a narrative interspersed with notations from the diary of Gun (Karina's mother) as she describes Karina's progress from birth through her sixth birthday. In the foreword, Dr. Carol Bower recommends the book as a source of inspiration that provides valuable information and is a pleasure to read. Sadly, that was not the experience of the reviewers.

The authors are careful to remind readers that children with Down syndrome are unique individuals, and that this family's experience is unique as well. They also acknowledge that the family tried too often to manage without taking advantage of available services and resources. Given the upbeat introduction, however, it was disappointing to encounter the heavy, sad tone of the book. Perhaps, the family was not provided with accurate information about appropriate developmental milestones and time tables for their daughter. There are frequent references throughout the book to Karina's delays and to how much longer it will probably take for her to reach particular goals. Much emphasis is placed on how tired the parents are all of the time and what a wonderful relief it is when Karina goes to a respite home for the weekend or to a week-long camp. This implies that it is impossible to have a normal family life and to participate in social activities if you have a child with Down syndrome.

The book contains some misinformation as well. In discussing feeding problems, the authors inaccurately mention that most children with Down syndrome have enlarged tongues. Instead, these children tend to have low muscle tone throughout the midline of the body. This includes the muscles of the tongue.

Overall, we would suggest looking at other sources if the intent is to offer a positive view of the early years with a child who has Down syndrome. Families and professionals could be encouraged to read Kumin's *Communication Skills in Children with Down Syndrome* (Bethesda, MD: Woodbine House, 1994) or Karen Stray-Gunderson's *Babies with Down Syndrome* (Rockville, MD: Woodbine, 1986). For upbeat, real-life stories, there is the delightful book *Down Syndrome: Birth to Adulthood* about and by families and young adults

with Down syndrome by Rynders and Horrobin (Denver, CO: Love Publishing, 1996) as well as Kingsley and Levitz's *Count Us In: Growing Up with Down Syndrome* (New York, NY: Harcourt Brace & Co., 1994).

Sandfort, Theo, ed. *The Dutch Response to HIV: Pragmatism and Consensus.* London, England: UCL Press (Distributed by Taylor & Francis, Inc., 47 Runway Rd., Suite G, Levittown, PA 19057-4700; 1-800/821-8312), 1998, 287 pages, $95.00 hardcover.

Reviewed by J. Gary Linn, Ph.D., School of Nursing, Tennessee State University.

The challenge of AIDS world wide has produced the best and the worst of institutional responses. This book gives a detailed account of the societal response to HIV in the Netherlands from the early 1980s until the mid-1990s. It is refreshing to read about a country whose central government responded to the perceived threat of AIDS with compassion and reasoned social policy rather than indifference; whose local communities chose to work with gays and intravenous drug users toward more effective treatment and prevention rather than to stigmatize or punish them; and whose healthcare system was widely accessible to the HIV-infected population rather than restricted to those fortunate enough to have health insurance.

The articles in this volume about the Dutch reaction to AIDS investigate many different issues. Section One covers prevention and discusses how it has been developed to meet the needs of various groups. General population campaigns and the rationales for them are discussed by Kok et al. Hospers and Blom give an overview of prevention programs developed by the federal government for gay men. Van Ameijden and Van den Hoek demonstrate how certain preventive efforts have constrained the growth of the HIV epidemic among injecting drug users. Vanwesenbeeck and DeGraaf write on prevention that targets sex workers and their clients and they discuss their own findings. Singels analyzes prevention activities aimed at migrants and ethnic minorities in the Netherlands.

Section Two is concerned with wider policy issues. In the first essay, Veenker shows that, even though the issue of AIDS was never politicized, national political parties had a major role in fostering an effective response to it. In the following chapter, one of the few significant conflicts in Dutch AIDS prevention is described. During the first ten years of the epidemic, gay men in the Netherlands were directed to abstain from anal sex. DeZwart and his associates analyze the sources of this message and how the message ultimately changed. Van de Boom and Schnabel next explore the reasoning behind dominant patterns of healthcare response together with the impact that AIDS has made on the healthcare system. Cognizant of the urgency of the problem of AIDS in the developing world, the Dutch government has given a high priority to prevention activities abroad. Moerkerk contributes a detailed account of these prevention programs in developing areas.

In Section Three, results from several major Dutch research projects are shown. Significant studies that heretofore have not been translated are highlighted. VanZesson and Sandfort analyze the Dutch general population survey on sexuality and AIDS that was unique for its time (1989) in western Europe. Bakker et al. summarize Dutch research on the social psychological determinants of safe sex among adult heterosexuals. Vogels et al. contribute data from a national survey of adolescent and young adult sexual behavior. Since this is a longitudinal data set with information from 1990 and 1995, it is possible to examine changes in sexual behavior which show an increase in the number of partners and a decrease in the age of first sexual experience. Finally, in another longitudinal study, De Vroome and his colleagues discuss the diffusion of safer sex in the Dutch gay population.

The central question addressed by *The Dutch Response to HIV* is why there is no AIDS epidemic in the Netherlands. By January 1997, there were only 4,350 cumulative reported cases of persons with AIDS. There is little evidence that HIV is a threat to the heterosexual population. The infection is restricted to gay males and intravenous drug users. After reading this book, it is apparent that the Dutch approach to HIV, in many ways, is

unique and will be difficult to generalize to a relatively higher infection country like the United States, which continues to report about 40,000 new cases of HIV per year. In the Netherlands, because of liberal attitudes toward homosexuality, gays were included from the early 1980s in the development of effective national HIV prevention programs. Also, progressive attitudes towards intravenous drug users meant that this population could be reached with a comprehensive harm reduction program which included prevention education and counseling, needle exchange and access to methadone, and high quality medical care. Furthermore, the Dutch have effectively restricted immigration, so large numbers of persons from areas of the world with high HIV infection rates are not permitted to migrate to the Netherlands.

A criticism of this book is that it does not cover the current HIV situation in the Netherlands. Most of the articles deal only with the period up to 1995. Another concern is the high price ($95.00) of the hardcover edition. Unless it is available in a much cheaper softcover volume, relatively few potential readers will be able to afford to purchase it. Nevertheless, this unique book should be of interest to public health scholars and policy makers, AIDS educators, social workers, and researchers interested in the social aspects of HIV in western industrialized countries.

Winston, Elizabeth, ed. *Storytelling and Conversation: Discourse in Deaf Communities*. Washington, DC: Gallaudet University Press, 1999, 227 pages, $55.00 hardcover.

Reviewed by Amy Terstriep, Department of Anthropology, Albion College, Albion, MI.

Storytelling and Conversation is the fifth book in the "Sociolinguistics in Deaf Communities Series" published by Gallaudet University. The focus of this volume is on discourse analysis which takes the linguistic focus beyond the sentence level to look at language in use and the cultural context of communications. Papers in this book describe studies in Bali, Italy, England, and the United States. A number of chapters are fairly technical for readers unfamiliar with linguistic terminology and notations, though keys to notations are often footnoted for those interested in sifting through. Much of the research in the book is hindered by small sample sizes, sometimes only two people. Still, a few chapters make the book very useful for people with interests outside of linguistics.

Several of the papers address ways that signers shape their messages such as a comparison of spatial descriptions in ASL and spoken English, a comparison of storytelling in ASL and spoken English, communications through text telephones in England, and the use of sign space in British Sign Language. The remaining essays discuss the integration of sign languages and deaf people into cultural and linguistic communities. These chapters are more broadly applicable to disability issues. For example, communications between Italian deaf parents and their hearing children are analyzed and the presence of an interpreter and the influence this has on communication are explored. Another chapter describes the use of narrative analysis in academic settings to develop bilingual (English/ASL) abilities in deaf students. The descriptions of the fundamentally different form of narrative in ASL will interest readers who work with deaf people.

Perhaps the most intriguing part of the book is the discussion of deaf people in Bali. While this chapter should be divided into two separate articles for clarity, it may well be worth the price of the book. The authors, Jan Branson, Don Miller, and I. Gede Marsaja, describe their linguistic and ethnographic work in a village with a hereditary deaf population (kolok) present for at least twelve generations. Sign language is used not only by deaf people, but also by the majority of hearing villagers. Deaf villagers are fully integrated into village life, partially because their identity comes from membership in kin and ritual communities. Their identity as kolok is irrelevant to the performance of family, clan, and village ceremonies. Deafness is also not marginalized in this village as it is seen as part of the diversity of nature and is a part of the origin myth of the village which includes a deaf god. The

authors also survey deaf people in the region. New political forces are pushing for linguistic uniformity which may affect the deaf population. The construction of deafness in this cultural setting and the possible changes that government interventions may bring make this a particularly interesting article for people involved in disability issues.

Although this book focuses on linguistic analyses, several chapters will intrigue readers interested in anthropology, Deaf and Disability cultures, and education and policy issues.

Books for Kids

Meyers, Cindy, and Morgan, Carol. *Rolling Along with Goldilocks and the Three Bears*. Bethesda, MD: Woodbine House, Inc., 1999, 30 pages, $14.95 hardcover.

Reviewed by Beth Franks, Hobart & William Smith Colleges, Geneva, NY.

If the proof of the porridge is in the eating, the proof of a children's book is in the reading. Although *Rolling along with Goldilocks and the Three Bears* was endorsed by several colleagues, I wondered how children would respond. A special education student teacher volunteered to road test it in her inclusive kindergarten class. With its colorful pictures, its familiar rhythms, and its new material, the book held the children's interest throughout its reading. I was struck by the reaction of one little boy, a child who wore braces and needed assistance in walking, sitting, and participating in most class activities. Although he usually daydreams during story time, the book held his attention. He did not contribute to the discussion and none of the other children turned to him when physical therapy was discussed, but he was riveted by the tale.

As the title suggests, this book is an adaptation of the familiar story about Goldilocks and her encounter with a family of bears. In Meyer's version, the three bears' house has been adapted as well - to accommodate Baby Bear's wheelchair. Because the three bears have decided to take Baby Bear to physical therapy while their porridge cools, Goldilocks is able to enter their home, sit in their chairs, eat their porridge, and fall asleep in Baby Bear's bed. After being discovered, Goldilocks explains her behavior to the family (she was lost and hungry). She tries Baby Bear's wheelchair finding that she can move easily, but her arms get tired. The tale ends with Goldilocks and Baby Bear becoming "the best of friends." The language of the tale is simple and direct, the pictures bright and engaging.

In assessing picture books much of the appeal for children will depend on how well the reader handles the material, although other factors come into play as well. This book, with its combination of the familiar and the new and its colorful illustrations, makes a compelling story. It has the further advantage of ending with a friendship between Goldilocks and Baby Bear, an element that charmed the kindergarten class. When my student teacher asked the children if they liked the new version, they all responded positively. When she asked what they liked best, one child, speaking for all, blurted out, "I want to make friends with that bear!" What more could one ask of a children's book featuring a character with a disability?

Rickert, Janet Elizabeth, and McGahan, Pete. *Russ and the Apple Tree Surprise*. Bethesda, MD: Woodbine House, Inc., 1999, 29 pages, $14.95 hardcover.

Reviewed by Timothy Lillie, Ph.D., The University of Akron, Akron, OH.

When I received *Russ and the Apple Tree Surprise* for review, I was puzzled: I thought that I was to review a book about disability or disabilities. The book seemed, to my casual eye, to be a typical children's book about somebody named Russ and his parents and grandparents. It dawned on me slowly that the boy at the center of this story was a boy with Down syndrome (about five or six years old, it seems). I was not sure that it was a book about a boy with Down syndrome, though, until I saw the subject title of "Down

Syndrome/Special Needs" on the back cover: Russ did not have the classic features of a child with Down syndrome, at least to my eye.

At first, this seemed to me to be a good thing. After all, is it not part of the task of our society to reduce or eliminate the stigma that still attends many disabling conditions? Is not this book a sign of progress? After all, it depicts a small boy spending a day with his parents and grandparents, one who wants a swing set on which to play. He learns how much fun it is to cooperate with parents and grandparents in picking apples and baking one's own apple pie and he is rewarded by Grandpa with a swing hung on the very apple tree from which he earlier got the apples for the apple pie. It is a sweet (maybe saccharine, to some) story and presents the image of a child having typical and age appropriate desires and family.

Well, maybe it is a good thing, but the problem that is not faced here is that, in presenting Russ as if he were "normal," the author risks ignoring the very real support needs that people with cognitive impairments may have. Russ is depicted as being able to play alone, communicate, cooperate, follow instructions, put a pie into the (hot) oven, and take it out again. The book presents these as if they occurred without effort, or with minimal training at best. Maybe they did, but children with Down syndrome typically experience some degree of mental retardation, which makes learning a little slower. It occurred to me that this book, in its presentation of Russ's capabilities, is (in a sense) the ultimate in the "social model" of disability: Russ is presented as competent because the author (with the help of the pictures) says so. Powerful as the social model is for explaining disability, sometimes it does not adequately describe the experience of disability which may have a physical or medical component. One would not wish to suggest that a return to medicalization of disability should be tolerated. It should not. However, there is a place for medical care, even of a specialized nature, in the lives of people with disabilities, as there is for people who are typically developing or not experiencing a disabling condition.

Finally, the author presents the men (Dad and Grandpa) as doing the "outdoors" work: setting up the ladder, carrying the basket of apples, building the tree swing. The women are the ones who do the washing, peeling, and baking of the apples. Russ helps both the men and the women, but the division of labor is clear. However, despite all these theoretical reservations (and they are real), I think that this book and those like it (this one is for children aged 3-7) have a place. Specifically, these books can break down the invisible barriers that well-meaning, but uninformed adults face when thinking about disability or when discussing it with their children. A lot more needs to be done to follow this up, but Russ can only do so much in any one day. Since this is the first of a series, be on the lookout for Russ at the firehouse and Russ in the classroom.

Video Clips

Basmajian, Sylvia (Producer), Amato, Adrienne, and Rogers, Derek (Co-directors). *First Break* [video]. Boston, MA: Fanlight Productions (4196 Washington St., Suite 2, Boston, MA 02131; 1-800/937-4113), 1997, 51 minutes, $195.00 purchase, $50.00/day or $100.00/week rental.

Reviewed by Barbara Granger, Ph.D., Director of Training & Dissemination, and Paula Gill-Phy, Peer Supports Counselor, both with Matrix Research Institute (MRI), Philadelphia, PA.

This film is very useful in that it jumps right into the very most personal experience of mental illness, following three people for a year. The film teaches the viewer general information about the difficulties with diagnosis, treatment, and recovery through the direct experiences of three individuals diagnosed with a mental illness for the first time. The film teaches about labeling and stigma through the eyes of the family and the person with the illness. *First Break*, cleverly, is not just about the illness itself; it also incorporates the breaks in

the person's whole network of everyday life - the first breaks of family relationships, friendships, housing, and work.

There are interesting contrasts of coping strategies among the three people and their families and it is a long year of recovery and patching together their lives. One important problem remains, however. By focusing on only three people clearly from "white middle to upper middle class," the film loses the power of comparison (similarities and differences) that poverty and/or cultural difference bring to the experience of a "first break." With this in mind, we recommend that this video be used for high school health education classes, introductory human services classes, and introductory sociology or psychology classes. However, teachers who use the video to generate dialogue reflecting on the many important concepts presented through the video should recognize the need to include additional teaching resources to support dialogue about issues concerning a multicultural or class impact on the experience of a "first break." In addition, this film may be used as an educational tool with family members of persons with a diagnosis of mental illness. However, again, it will be very important for the instructor to address these same cultural, stigma, and caretaking issues, as there are interesting contrasts among reactions of family members in this film.

Basmajian, Silva (Producer), Amato, Adrienne, and Rogers, Derek (Co-directors). *First Break* [video]. Boston, MA: Fanlight Productions (4196 Washington St., Suite 2, Boston, MA 02131; 1-800/937-4113), 1997, 51 minutes, $195.00 purchase, $50.00/day or $100.00/week rental.

Reviewed by Maneesh Gupta, Master's in Occupational Therapy Student, Lewiston-Auburn College of the University of Southern Maine, Lewiston, ME.

First Break brings forth a compelling insight to the reality of mental illness. The three young adults in the film are all introduced as having a mental illness that has a tremendous impact on their daily lives. The film also examines how the families of these individuals are affected by their illnesses.

The stories of Simon, Ariadne, and Shely are similar in that they all share mental illness, but different because each has a different type of illness. Schizophrenia, bipolar (manic-depressive) disorder, and a brief psychotic episode are the three types of illnesses described in the film through the eyes of these young individuals.

Simon's contact with schizophrenia is as real to the viewer as actually having the illness himself/herself. Schizophrenia is described as a brain disorder that impairs Simon's ability to think clearly, manage his emotions, make decisions, and relate to others. Simon discusses his hallucinations and delusions in a way that makes the viewer step into his shoes and feel what he is going through.

Shely is a young adult who was under a lot of stress at the time of her first psychotic episode. She is seen not only as a person with mental illness, but also as a loving mother.

Ariadne suffers from bipolar affective disorder. She is often seen as being sad and unmotivated and as having disturbances in sleeping and eating patterns. These are just some of the symptoms resulting from her mental illness.

I thought *First Break* was extremely beneficial to me as an occupational therapy student because it opened my eyes to the reality of the client's emotions and perceptions. Much too often in health care settings health care providers neglect to listen to the client's life story, interests, and roles. They often work to fix the client's mechanical or cognitive problems without paying close attention to their hobbies or meaningful activities. They forget that there is a person inside the body that they are treating on a strictly scientific level. *First Break* provides a deeper understanding of mental illnesses and helps to broaden one's knowledge of how life is affecting the person. I wish that I had seen this film before the Level I Fieldwork that I did at a mental health setting because it would have provided me with much

needed insight to be more sympathetic and understanding to people experiencing similar illnesses. I would recommend this film not just to those viewers who plan to pursue a career in mental health, but also to those who plan to practice in any medical profession.

Conquest, Wendy, Drake, Bob, and Elliott, Deni (Producers/Directors). *The Burden of Knowledge: Moral Dilemmas in Prenatal Testing* [video]. Boston, MA: Fanlight Productions (4196 Washington St., Suite 2, Boston, MA 02131; 1-800/937-4113), 1994, 54 minutes, $145.00 purchase; $50.00 rental/day.

Reviewed by Gail Landsman, Anthropology Department, State University of New York at Albany.

How much knowledge do we want? Does more knowledge make for "better" choices? This provocative documentary gives no definitive answers, but, rather, chronicles the pain and responsibility visited upon couples as they encounter the option of prenatal testing. While pregnant women's experiences with prenatal testing are commonly described in terms of anxiety, this video suggests that such descriptions trivialize what people actually face. To accept or to refuse prenatal testing or, in response to a positive test result, to choose either to selectively abort or to give birth to a baby with a genetic defect are indeed personal decisions made within the context of individual families, but they also represent struggles with some of the greatest moral dilemmas of a technological society.

This highly recommended video will be valuable in courses in Disability Studies, bioethics, and social science courses dealing with reproduction and parenting. It provides clear explanations and depictions of prenatal screening and diagnostic tests. More importantly, it follows the experiences of different women and men from the point of making decisions whether to use or to reject prenatal tests through to the consequences of their decisions. Thus, the film does not stop with the news women receive. Instead, we learn about the emotional and practical aftermath of choosing selective abortion, the experience of finding out at birth that one's child has a disability, the experience of receiving news about Down syndrome through amniocentesis and using that knowledge to prepare for the birth, and, finally, various parents' honest reflections on the joys and difficulties of raising children with disabilities. By enlarging the time frame of prenatal testing beyond the initial decision-making process, this film presents a truer picture of the long-term impact of testing on people's lives and insight into family life with children with disabilities.

The film includes the comments of medical researchers, social scientists, genetic counselors, midwives, physicians, and disability activists. I found it disconcerting at first that speakers were not identified by name or occupation in the film. By the end of the video, however, I had come to appreciate this strategy for the film makers had denied me the opportunity to make easy pre-judgments based on what I might perceive as a speaker's vested interest. Names and titles of all participants appear with their photographs during the credits. The film itself concludes aptly with commentary from one interviewee to the effect that decisions about prenatal testing engage us in asking what is ultimately an unanswerable question: What is the meaning of life?

Conquest, Wendy, Drake, Bob, and Elliot, Deni (Producers/Directors). *The Burden of Knowledge: Moral Dilemmas in Prenatal Testing* [video]. Boston, MA: Fanlight Productions (4196 Washington St., Boston, MA 02131, 1-800/937-4113), 1994, 54 minutes, $145.00 purchase, $50.00 rental/day.

Reviewed by Tom Holz, Master's in Occupational Therapy Student, Lewiston-Auburn College of the University of Southern Maine, Lewiston, ME.

As medical science continues its relentless march forward, society is increasingly confronted with ethical dilemmas that cannot be solved collectively; the burden of complex, often agonizing decisions is then placed upon the individual. Ethical dilemmas created by

prenatal testing, such as the alpha-fetoprotein (AFP) test and amniocentesis, are the controversial subject of *The Burden of Knowledge.*

Pregnant women, particularly those over thirty-five years of age, are routinely provided with a maternal serum alpha-fetoprotein screening test that identifies those expectant mothers who are at "higher risk" of delivering a baby with problems such as spina bifida or Down syndrome. Women found to be at risk must decide whether to use amniocentesis to determine the existence of genetic abnormalities in their unborn child. If the results of amniocentesis indicate that the child has a birth defect, the parents are faced with the life or death decision to keep or to abort their baby.

Rather than utilizing a narrator or interviewer to present and discuss the issues surrounding prenatal testing, the producers of this film spliced together snippets of interviews with scientists, academics, medical experts, and expectant parents facing the challenges presented by the screening and diagnostic procedures. Unfortunately, none of the interviewed professionals are actually identified before the end of the film and it is difficult to know what knowledge or beliefs motivate their comments on specific concerns such as abortion or disability rights. Because of the lack of a narrator and the constant switching from one speaker to another, the film is somewhat disjointed and difficult to follow at times leaving the viewer wishing for a more coherent in-depth analysis of the issues.

The overall strength of the film is the emotional testimony provided by the women and men who have actually experienced the moral debates created by prenatal testing. Some who decided not to go ahead with amniocentesis described the "harassment" they received from friends, family, and genetic counselors because of their decision. Others described the internal agony of deciding to abort a child that they felt they would not be able to raise. Ultimately, the film provides much insight into the intellectual and emotional struggles, along with the outside pressures, faced by parents who learn that their child may be born with a disability.

Hadary, Susan H. (Producer), and Whiteford, William A. (Director). *King Gimp* [video]. Baltimore, MD: Video Press, 47 minutes, $75.00 purchase.

Reviewed by Beth Haller, Towson University, Towson, MD.

First, let me disclose that the subject of *King Gimp*, Dan Keplinger, is a former student of mine. I was aware of this documentary long before it was nominated for the Academy Award that it won for Best Documentary Short on March 26, 2000. I have had Keplinger and film maker Susan Hadary speak to my classes. But I believe my connection to the film and my background knowledge allows me to relate some crucial "behind-the-scenes" information which is, in part, what makes this such an excellent documentary.

Hadary and Whiteford have a long history of creating non-stigmatizing documentaries about children with disabilities. They began this series of projects more than 15 years ago and have won several Emmys for films such as *Bong and Donnell and Rachel, Being 5.* Their approach, which spans numerous years of a child's life, fills their work with many real moments, rather than meaningless sound bites.

For example, *King Gimp* came to life from more than 100 hours of video footage. Dan Keplinger's story, the last in Hadary and Whiteford's series on children with disabilities, depicts 14 years of his life. And, by the time they were ready to cut the film into its final version, Keplinger was a college student, majoring in mass communication and minoring in art. Because the film makers understand the misrepresentations of disability that flow through mass media, they were committed to giving Keplinger his own voice in the film. So Dan Keplinger, in essence, became the screenwriter for his own life story. He viewed the years of footage of himself, and, then, at Towson University, he did an independent study with film professor, Greg Faller, to shape an 80-page script. I believe this to be the most important aspect of the behind-the-scenes of *King Gimp* - Dan Keplinger is in control of his media rep-

resentation.

One of the biggest decisions for the film makers was how Keplinger would communicate in the film. Keplinger, who has cerebral palsy, has a serious speech disability, making it difficult for him to be understood. He typically communicates by tapping words onto his laptop with a headstick. They went through several communication ideas: an actor speaking for Keplinger, subtitles, or a voice synthesizer. Keplinger was very opposed to a voice synthesizer because he says he cannot convey his emotions that way and people talk to the computer, not to him. Susan Hadary said, as film makers, they would only make a film that embraced Keplinger's wishes even if it meant they lost funding for the film. In the end, Keplinger and the film makers developed the perfect representation of his communication style. He speaks verbally throughout the film and his words are typed out as subtitles, a truly on-the-mark portrayal.

Finally, most of the film, in addition to following Keplinger from childhood to adulthood, focuses on his development as an artist. Creating art has become his passion and his way of communicating his complex emotions to the world. The beauty of the film is that it really is about an artist growing up. And he just happens to have a disability.

King Gimp appeared on HBO June 5, 2000, and is available for purchase from Video Press, 1-800-328-7450, or at <www.videopress.org> under pediatrics.